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# **Women's Health Information Network Project Summary**

for the Ministry of Women's Equality

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# Introduction

The VWHC has been involved in the provision and exchange of women's health information locally, provincially, nationally & internationally since 1972. We do this work because we believe that only by empowering women to make their own health care choices can they have control over their health. We also understand that, in order for those health care choices to be honored, the health care system and the research & policy development that feeds that system must change.

In 1992, after an extensive review of our organization and the services we provide, we came to the conclusion that our services needed to be updated to better meet the needs of the women of BC. Accessibility and the blending of information provision with advocacy became our main focuses. Given this mandate, we began creating a province-wide system of health information delivery that was dynamic and could be used as a community development tool.

The Women's Health Information Network (WHIN) is such a system. It answers the need for accessible health information and provides the means to build community-specific and province-wide networks. Each of the components of the system is based on the model of health information delivery and advocacy work for which the VWHC is already well known. The computerized information aspect of the system is designed to support a network of community health advocates, in the same way as our Information Centre now works with our Health Help-line workers. In using WHIN as a tool for community development of women's health care, we feel that we can maximize the changes the provincial government has introduced in health care reform to benefit women.

The herstory of the VWHC speaks to why we would be an appropriate sponsor for this province-wide program. The strength of our work has always been the passion of our volunteer collective members. For 25 years, our volunteer collective members have given freely of their time and expertise to help women help themselves. For 25 years, our volunteer collective members have been researching the kinds of health information women need. Through educational programs, publications and workshops, direct advocacy and lobby work, our health information resource centre, specific research projects, mail order service and our health help line, we strive to provide women with access to health. The WHIN is a natural continuation of this work.

# The Development and the Need for the WHIN

In the fall of 1992, the VWHC received a grant from the Ministry of Health to explore the development of a computerized women's health information network for BC. During the next 2 years, two separate studies were conducted. A province-wide needs assessment of organizations (based on survey & focus groups methodology) with regards to the usefulness and expectations of a computerized health information system resulted in a list of guiding principals for the content and the end-user requirements of WHIN. In 1994, a study of the need for community health care advocates<sup>1</sup> (survey & focus-groups methodology) has defined both the advocacy-specific contents of the database and the role of the community health advocate.

In 1993, our progress-to-date was presented at a meeting of the Canadian Women's Health Network (CWHN) in Winnipeg. We are aware of the CWHN's current proposal<sup>2</sup> for the Centres of Excellence competition, and, as a member of the Network, the VWHC will continue to work with them to ensure that the WHIN will ultimately dovetail with their proposed work.

The recommendations from the 1993 province-wide Women's Health Conference<sup>3</sup>, the tri-city study on Women Finding Health Information<sup>4</sup> and, most recently, the consultation report by the BC Women's Hospital<sup>5</sup> the VWHC's decision to expand upon its existing programs through a system such as the WHIN. These studies speak to the need for 1) accessible information about issue specific health concerns and how the health care system works, 2) a central clearinghouse for information to reduce waste of resources, and 3) a basis in women-centred values.

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<sup>1</sup>Is There A Need For A Community Based Health Advocate? A report by the Vancouver Women's Health Collective for the Ministry of Social Services and Housing, 1994

<sup>2</sup>Discussion Paper: Strengthening the Links: A Framework for the Expansion of the Canadian Women's Health Network and its Relationship to the Centres of Excellence for Women's Health Program; Anne Rochon Ford for the Women's Health Bureau of Health Canada, Dec. 1995

<sup>3</sup>Women's Health Conference: Moderators Report; Ministry of Health and Ministry Responsible for Seniors, 1993

<sup>4</sup>Finding Health Information: Women's Experience; Marion Crook for the Port Coquitlam Area Women's Centre Society, 1994

<sup>5</sup>The Challenge Ahead for Women's Health, BC Women's Community Consultation Report; Consultation Working Group, Sept. 1995

## Overview of the WHIN

The WHIN has 2 components - computerized databases and community health advocates.

The databases are designed to be user-friendly and will be accessible to anyone at one or all of the following places: women's centres, community health centres, community centres and public health units (depending on a community's need and resources). These sites reflect the WHIN's underlying philosophy of integration with the community services that already exist. It should be a tool that these services can use, not a stand-alone service. The maintenance and updating of the databases will be the responsibility of the VWHC, and funding will be accessed through regional, provincial, federal, foundation and corporate sources.

The community health advocates (CHA) will work out of these centres and use the databases to help women make better health care choices. This component of the program is designed to be accessed at the Community Health Council level. This is the level at which women can have direct say about their health information needs. The Community Health Council will be expected to support the program by providing money to set up the community-specific training of the CHAs, ensuring support through space and equipment allocation in the various centres, translating materials as needed, and providing feedback information to the database.

CHC.

### Computerized Health Information Databases

#### The System

The VWHC has engaged Columbia Redpoint Information System Inc. for the actual development of the computerized database system. We currently have a shell program that we have been using to evaluate the end-user friendliness of the system. The design considerations are audience, language level, clarity of presentation, accessibility, computer literacy level required, ease of use, intuitiveness, comprehensibility, wording & terminology and overall tone/style. The following are some selected highlights from the pre-production overview of the database component of WHIN. Outlined here is a proposed guideline designed to serve as a template for the final product (to be adjusted as per our evaluation process).

#### Pre-Production Overview

This database management system is designed to provide simple and efficient access to information on special health-related topics. Currently two areas of information are covered:

### 1) Health Care Providers

A database of people resources - practitioners, organizations and support groups - in the community that will include a variety of fields such as:

Hospital/Clinic	:	The name of the organization to which the practitioner belongs.
Organization	:	The name of any affiliated organization or government bureau.
Location	:	The name of the city or town in which the group operates.
Specialization	:	Area of specialty.
Method or Activity	:	Methods used.
Languages	:	Languages spoken.
Gender	:	
Community Feedback	:	Evaluation of service

### 2) Information Resources

The Information Resource database serves as an on-line guide to available print, tape, and film resources and includes information on title, author, language in which the work is available, and a series of applicable key words. Printed output from the Information Resource database will provide complete information on the work including, among other things, the information listed above, name of the publisher, and of printing, medium(s) upon which the work is available, ISBN number, and an abstract evaluation and description of the content.

### System Requirements

Although speed of database searches always relies directly on the speed of the computer performing the search, the WHIN system will function on minimal equipment. We will recommend that, where possible, a 486 type computer and a colour screen are used, but, if necessary, the program should run on an XT system with a monochrome screen and 640k of memory. We will recommend that minimum of 20MB hard disk space be available, although this requirement may grow considerably as the quantity of information in the databases increases.

The computer should use MS-DOS or PC-DOS version 3.30 or later. It will be possible to run the program as a DOS task under MS Windows version 3.0 or later, although this option is not recommended since it will slow operations somewhat. It will also be possible to run the system as a DOS task under IBM OS/2 version 2.0 or later.

## Networks and Multitasking Systems

The WHIN program will be networkable and will run on most network systems including Novell Netware 2.x through 4.x, Novell Personal Netware, and Artisoft LANtastic. Some specific instances may experience performance degradation when the WHIN software is being used. These include:

- Running on a peer-to-peer network such as Novell's Personal Netware or Artisoft LANtastic.
- Running on a Novell Netware 286 or Netware 386 workstation which is using the RPRINTER remote print spooling system. (Printing may become very slow while the application is being used).
- Running on a multitasking system such as OS/2 or PC-MOS.

In these cases a special version of the program will be available which will eliminate these problems. We will not supply this version by default since it is expected that a small minority of installations will experience this problem, and the regular version of the program performs slightly better than the modified version. Apart from performance, there should be no visible difference between the two.

## Use of System

In order to keep operation of the system as simple as possible, every attempt will be made to use the same search system between different database systems. Although the names of the fields will change, and, to a certain extent, the type of material will be different, the logic of using the search system will remain largely the same. The system will be menu-driven and areas of user-input will be prominently highlighted. Various interactive boxes will guide the searcher in use of search criteria.

## Maintenance.

The maintenance portion of the system will be provided as a separate program, rather than integrated into the main system. Designing the system in this manner should simplify maintenance to the development code, since there will be only one version of the search system and one version of the maintenance program.

The functioning of the maintenance program will be menu-driven. Facilities will be included to add, delete, and modify records in all three databases and to pack databases.

## Content

There are several content considerations for which guidelines will have to be created:

- the criteria for inclusion
  - relevance, perspective, level, audience, date
- scope of subject matter to be included
  - how to define "health information"
  - appropriateness
- scale of information
  - how much can be verified, updated
- sources of information
  - if include information from other organizations:
    - consistency, compatibility of records from other systems
    - how to avoid duplication of information
    - updating procedures - time & effort involved
  - copyright/licensing
  - commercial availability of other products (CD-ROMs etc.)
- levels of treatment of materials(i.e. depth of analysis of books vs. articles etc.)
  - provide subject terms, abstract, evaluation for all types of material
  - framework for abstraction
- language, terminology, standardized subject terms
- data entry standards
- evaluations: framework; adherence

While the VWHC has done work in this area, we feel that we need to set up a Community Policy Development Committee to further develop these guidelines. This committee would pull together other librarians, members of other community information referral services, women's organizations, academics, and members of specific communities. This process would produce sound guidelines and create a greater web of support for the system between information and facilitation of the service. To date, all community information & referral services have been very supportive of the project.

### Resource Development

We have considered the acquisition of resources from two perspectives. First, as mentioned above, once the content considerations of the Information Resource Database has been clarified - the acquisition of resources will be dealt with. As it stands now, we have entered the contents our entire information centre into a pre-production database. One complete resource that will be available will be the fact sheets for specific women's health issues that the VWHC continues to produce. Given that this information has met the community needs over the last years, we felt it could serve as a good information basis from which to start. This also allows us to proceed with pilot testing that will give feedback to the development of guidelines.

Secondly, acquisition of data for the Health Care Providers Database will stem from a different process. In order to make this database community specific, we need local

feedback about what is available. The regional information & referral service, along with resources found in the public health units and women's centres, will be continually solicited using the community health advocate as a focus. Therefore, the completeness of the databases, as far as usefulness to the regions, will depend on information sharing, especially with regards to the local resources and referrals. In other words, the databases will be updated with new and modified data and information as it is submitted to the VWHC and updated copies of the databases will be redistributed to the regions. It is not our intention to increase the number of locations where women have to go for information, but to assist women in finding information that exists. Part of our database's function is to be able to inform women of the location of resources. We currently have more than 2000 resource listings for the province entered in the pre-production databases.

### **Mail Order Service**

The ability to access resources cited in the databases can be dealt with in several ways. VWHC has had a mail-order service which has dealt effectively with health information requests for over 12 years. A location tag will be added to resources to help with the location process. We are also exploring linking up with a business that could facilitate the ordering of books not found in the region. We would also continue to share our listing of resources with the libraries throughout the province.

## **Community Health Advocacy Program**

The need for a Community Health Advocate Program was very clear in our 1994 study. Based on the strength of this study and previous experience, the VWHC received funding through the United Way to design a Train the Trainer Program for Community Health Advocates - community identified individuals that will use the WHIN databases to provide various forms of direct health care advocacy for women and to train their own community members in advocacy work thereby widening the base of support available to women.

Objectives of the program are to:

- create a community advocacy steering committee from a cross-section of provincial women's organizations
- research and develop a manual of standard information to be used in training
- develop training program workshops
- train Community Health Advocates in interested communities such as those of houseless women; rural women; Indo-Canadian women; Arab women; Muslim women and lesbians.
- work with these communities to select the women for the program and ensure that there is ongoing community support for the women once the training is done.
- encourage and support the development of Health Advocacy Programs in all regions by directly approaching, and promoting programs to, Community Health Councils



While the initial training for the program will be centralized at the VWHC, the objective is to support the development of training at a community level. The manual will be designed to ensure that any translation needs are facilitated. The program will run on the same basis as the VWHC information centre; we train volunteers to do volunteer work. If funds can be obtained at the community health council level to pay for CHAs, we will access them, but we feel it is prudent at this time to set up the program for a volunteer work load.

## **Relationship to the BC Consortium & National Health Organizations**

We are currently working with the Canadian Women's Health Network, a group of which we are a member, to ensure that our databases will dovetail with their national database of Who's Who across Canada in the Women's Health Movement.

## **Networking & Research**

Given that the WHIN is targeted for women's centres, community health centres, community centres, and public health units, it could provide an important link to the Centre of Excellence. The very nature of the system ensures that there will be constant feedback about regional & local health care needs and specific health concerns. We will likely place a counting system in the databases that will give us hard data about what topics are accessed over a specific period of time. Also, the information about who is doing what and where will be constantly updated.

We have also considered the option of setting up a bulletin board on the internet with a back door into the databases. This system could be used for lobbying and as an immediate means of communication between CHA, but it could be used in various ways: posting research results, news flashes and population recruitment for studies. Electronic mail use is growing in the grassroots community and is being facilitated through the new initiatives being put forth by the Ministry of Women's Equality. WHIN can only benefit from working with the Centre of Excellence through improved access to and acquisition of information, refined direction to guidelines, cost reduction through shared expenses, and, of course, the possibility of funding.

## Selections from Letters of Support Received to Date

BC Coalition for Abortion Clinics, 219-1675 W. 8th Ave , Vancouver, BC V6J 1V2

*WHIN would prove to be a valuable resource to BC women, not only providing important health-related information, but that it will put the control of that information in the hands of women.*

big sisters of BC Lower Mainland, 34 East 12th Ave, Vancouver, BC V5T 2G5

*Women's...right to informed decision-making in regards to their own health care requires that there be a way for them to find current information. Your proposal to use available technology to create an accessible tool...is most welcome and necessary.*

The Aurora Centre, BC Women's Hospital, 4500 Oak St., Vancouver, BC V6H 3N1

*The database will provide a greatly needed resource for women looking for health practitioners who are sensitive to women's needs.*

Battered Women's Support Services PO Box 1098, Postal Stn. A Vancouver, BC V6C 2T1

*We believe that the use of feminist community advocates is an integral part of effective service to all women.*

Registered Nurses Association of BC, 2855 Arbutus St. Vancouver, BC V6J 1V2

*RNABC supports the general policy of women having greater access to health information and support networks to enable them to make informed decisions regarding their health care options and healthstyle choices.*

Positive Women's Network, 1107 Seymour St., Vancouver, BC V6B 5S8

*An initiative like the WHIN will broaden the choices available to women, strengthening their ability to manage their health care.*

REACH Community Health Care, 1145 Commercial Drive, Vancouver BC V5L 3X3

*The information that women are given is often confusing and complicated...they face barriers to making sense of the information they receive.. some are unfamiliar with medical jargon..some are ESL...some cannot afford to travel to the VWHC. WHIN offers a solution to all these barriers.*

SHEWAY, 455 E. Hastings Street, Vancouver, BC V6A 1P5

*The Information Network would allow women to self-educate about their health care needs, to research physicians and other health care providers, and to be empowered by this process.*

Western Institute for the Deaf and Hard of Hearing, 2125 West 7th Avenue, Van BC V6K 1X9

*A clearinghouse of information which can be accessed via computers at women's centres and elsewhere is an ideal tool for women who are Deaf or Hard of Hearing, and who often encounter communication barriers in their search for information.*

**Single Parent Resource Centre, 602 Gorge Road East, Victoria, BC V8T 2W6**

*A Women's Health Information Network with community advocates is very much needed and the Single Parent Resource Centre would welcome this necessary service.*

**Equity Office, U.B.C., Room 306, Brooke Hall, 1874 East Mall, Vancouver, BC V6T 1Z1**

*We applaud the availability of these databases in the communities around the province. The more direct and local this information is, the better that women and their families will be served*

**Port Alberni Women's Resources Society, 3048 Fifth Avenue, Port Alberni, BC V9Y 2E3**

*WHIN would be a valuable tool for women to take charge of their health needs, which is crucial to equality. The need is there: WHIN must be made more widely available and putting it in place at women's centres and community health clinics is an excellent way to do that.*

**Maple Ridge Alcohol & Drug Counseling, 22477 Lougheed Highway, Maple Ridge, BC V2X 2T8**

*Easy access to gender appropriate information is an essential tool for the improvement of women's health.*

**Westcoast Women's Resource Centre, P.O. Box 868, 1509 Peninsula Road, Ucluelet, BC**

*We feel WHIN proposed by the VWHC is a valuable project worthwhile of funding, and would greatly assist us in improving our ability to provide accurate, up-to-date information on health issues to the women we serve.*

**Sunshine Coast Women's Centre, 5645 Wharf Road, P.O. Box 1443, Sechelt, BC V0N 3A0**

*Women want to be in charge of their health decisions ... and are fully aware that in order to make these decisions they must have information of the types that the WHIN databases will provide.*

**Shuswap Family Resource & Referral Centre, Box 914, Salmon Arm, BC V1E 4P1**

*The proposed WHIN would be widely used by our consumers.*

**Safe Haven Centre, Box 168, Burns Lake, BC V0J 1E0**

*We believe through these kinds of resources and with the information available to us, that a lot of health related issues will be able to be dealt with more effectively.*

**Prince Rupert Transition House, P.O. Box 907, Prince Rupert, BC V8J 4B7**

*A central clearinghouse of information will reduce the effects of geographical isolation and establish an essential network for providing the public with educational and resource materials.*

Faculty and Staff Association, University College of the Fraser Valley, 33844 King Road, Abbotsford, BC V2S 7M9

*The call for health councils to fund local health advocates for women will work to ensure that women are included in the regionalization of health care in BC*

The Pacific Foundation of the Advancement of Minority Equality/GLC, 1170 Bute Street, Vancouver, BC V6E 1Z8

*This plan will serve to empower many women--especially marginalized women to make appropriate decisions for themselves.*

Simon Fraser University Women's Centre, AQ 2003, S.F.U., Burnaby, BC V5A 1S6

*Real choices can only be made when information on options is available.*

Women's Resource Society of the Fraser Valley, Abbotsford Transition House, BOX 3044, Mission, BC V2V 4J3

*We believe such a network, available on-line throughout the province, will provide accessible information to all women in British Columbia.*

Vancouver Richmond Mental Health Network, 109-96 East Broadway, Vancouver, BC V5T 4N9

*A project such as yours would be of great help to women seeking alternatives to psychiatry and ways of empowering themselves.*

Roxanne Davies, 1118 Wendel Place, North Vancouver, BC V7K 2W1

*The government is urging people to practice good health measures, to take an interest in their health and to be wise consumers of limited medical dollars. The addition of a medical information service for women will be of great benefit to the entire medical system.*

Girls' Alternative Program-GAP, Options For Pregnant/Parenting Teens, Options Daycare, 3020 Richmond Road, Victoria, BC V8R 4V1

*Having an opportunity to access information and referrals specific to women's health concerns that are not racist, sexist, etc. would be a valuable tool. Often fear and shame keep women from getting help that is out there; having someone to help bridge the gap could provide invaluable.*

The Acupuncture Association of British Columbia, 1367 East 41st Avenue, Vancouver, BC V5W 1R7

*The inclusion of "community health advocates" in the package would add a further tool for empowering women to manage their own health care.*

British Columbia Medical Association, Council on Health Promotion, 115-1665 West Broadway Vancouver, BC V6J 1V2

*Any system that increases a person's knowledge of the health-care options available today will also help that person make more informed choices.*

**Screening Mammography Program of British Columbia, #414-750 West Broadway, Vancouver, BC V5Z 1H3**

*The Women's Health Information Network proposal (utilizing electronic means to provide health information) would be timely and beneficial to the women to British Columbia.*

**End Legislated Poverty, 211-456 West Broadway, Vancouver, BC V5Y 1R3**

*Access at the community level of the information being supplied through WHIN and, importantly, the assistance of "community health advocates" will help make health care and choices more accessible for women who may otherwise find themselves outside the mainstream, due to income situation.*

**Bridges for Women Society, BOX 5732 Station B, Victoria BC V8R 6S8**

*Access to understandable, women-oriented health information could be one of the tools that assist in rebuilding lives free of abuse. What a valuable resource the community health advocates would be for Bridges women as mentors in the health system.*

**Vancouver Lesbian Connection, P.O. Box 65951, Station F, Vancouver, BC V5W 5L4**

*We believe that this project will have many benefits to our community, as lesbians face many barriers to health services such as homophobic reactions as well as outright refusal of service from medical practitioners.*

**Elizabeth Fry Society, 101-2666 Queensway, Prince George, BC V2L 1N2**

*Many women find the current health system intimidating and inaccessible.*

**Ktunaxa/Kinbasket Tribal Council, SS #3, Site 15, Comp 14, Mission Rd., Cranbrook, BC V1C 6H3**

*On an individual basis, access to a resource database will reduce uncertainty and resistance in health issues surrounding most First Nations' women.*

**Helping Spirit Lodge Society, 39665 Dumfries Street, Vancouver, BC V5N 5R3**

*We know it is very important that women know all the options that are available to them in the community in health and other areas affecting their lives. The idea of having 'Community Health Advocates' who will be trained to assist women is an idea that deserves merit.*

**Elizabeth Bagshaw Women's Clinic, 40-3195 Granville Street, Vancouver, BC V6H 3K2**

*Wellness and prevention of disease are best achieved when women are empowered with knowledge, skills and resources. The proposal to develop 'Community Health Advocates' to assist and support individuals and groups of women in accessing and utilizing health care is instrumental to making WHIN truly meaningful and effective.*

**Fernie Women's Resource and Drop-In Centre, Box 2054, Fernie, BC V0B 1M0**

*Many women seek health information from our center. Having a full database at our fingertips will be invaluable.*

**BC Nurses' Union, 100-4529 Canada Way, Burnaby, BC V5G 1H1**

*The WHIN project proposal is an important resource tool for nurses both as women and as patient/client advocates.*

**Cariboo Friendship Society, 99 South Third Avenue, Williams Lake, BC V2G 1J1**

*We definitely need this type of information in our community, at the grassroots level.*

**BC Institute on Family Violence, 290-601 W. Cordova St., Vancouver, BC V6B 1G1**

*We ourselves contributed a computer database of information of family violence resources that will be included in the WHIN resource database.*

**Career Link, 4727 Marine Ave., Powell River, BC V8A 2L2**

*In our community, access to this health information network will support more informed choices among women seeking health care services.*

**Avalon Women's Centre, 5957 West Boulevard, Vancouver BC V6M 3X1**

*With health care systems changing so rapidly, the need for self-education, information and access to support networks is greater than ever.*

**BC Woman Magazine, 704 Clarkson St., New Westminster, BC V3M 1E2**

*Given the current government's commitment to furthering women's rights, and to finding cost-effective, user-friendly, community-based health-care options, I think that WHIN would be a wise funding choice.*

**YMCA-YWCA of Kelowna/Westbank, 375 Hartman Rd., Kelowna BC V1X 2M9**

*Traditionally, women have not received adequate information about their health...they have been expect to trust, without adequate explanation, that their doctors know better...Women are often intimidated ...and simply accept the information they are given. Your approach to resolving these issues with the development of an information network that is simple to access and understand is to be commended.*

**Cythera Transition House Society, 22318 McIntosh Ave., Maple Ridge, BC V2X 3C2**

*What a wonderful idea!*